

THE STATE OF AGING

INFORMAL CAREGIVING

EXECUTIVE SUMMARY

Beginning in the mid 1990's, the Senior and Long Term Care Division of the Montana Department of Public Health and Human Services (DPHHS) began looking into the affects that aging population trends would have for Montana and its senior population. In March 1999, DPHHS produced the first **State of Aging in Montana**, which looked at how state government viewed the impending aging demographic trends. The 1999 Montana Legislature subsequently passed House Bill No. 275, amending Section 52-3-101 of the Montana Code, and requiring the DPHHS to produce a biennial report, with annual updates, on statewide and community issues related to aging.

The 2000 Aging Report expanded on the 1999 report. The 2001 Aging Report looked at the same issues for local governments and local aging programs. The 2002 Aging Report examined the impact of health care work force shortages on people's ability to receive care through community-based services.

The 2003 State Of Aging in Montana report focuses on the issue of **informal caregiving**. This important issue is being highlighted for several reasons.

- The topic of informal caregiving complements last year's report dealing with health care work force issues. Informal caregiving represents another method by which people get their long-term care needs met. Since there are not enough health care workers to meet the current demand in community and institutional settings, informal caregiving serves a critical workforce function. While most informal caregivers provide care by choice, some continue to provide care or get into providing care because of the lack of qualified formal caregivers.
- For someone who needs help to remain at home, informal caregiving represents an invaluable commitment by family and friends to provide help across a broad spectrum of tasks ranging from help with shopping or getting to medical appointments to help with feeding and bathing and beyond. Because of its informal nature, it happens in the privacy of the home and often goes unnoticed by the public at large. However, informal caregiving represents how the majority of people in this county receive long-term care.
- The report establishes baseline data for Montana as it begins its efforts to develop caregiver services under the National Family Caregiver Support Program, a national program developed to support informal caregivers.
- Informal caregiving is intrinsically valuable because it strengthens family and community bonds.

- Caregiving is an issue that will have significant social and fiscal consequences for Montana and its growing elder population. Any decline in the prevalence of informal caregiving could have a significant impact on government supported health care programs and their budgets.

DEFINING CAREGIVING

Caregiving is a global term that encompasses a large range of situations that cross medical conditions, age groups, care settings and personal situations. It is an important component of the long-term care system. Caregiving focuses on the basic need for assistance regardless of who or how it is being provided. Used in its broadest sense, it can cover formal caregiving settings ranging from institutional settings like nursing homes to Home and Community Based Services such as the Medicaid Waiver and the Personal Care Program to in-home services provided through the Aging Network. In its most intimate sense, it can be families, friends and neighbors taking care of their relatives and friends in their homes. It is the latter that this report focuses on.

Informal caregivers are individuals who provide care to a relative or friend (a care recipient) that allows them to remain in their homes and their communities. In this report, we have chosen to use the term informal caregivers because it is more inclusive - it is better at capturing the broader scope of the caregiving experience. It includes not only family caregivers, but also friends and neighbors as well. In a rural state like Montana, all these elements are important components of caregiving. For purposes of the 2003 State of Aging report, we are concentrating on informal caregiving that involves people who are 60 years of age or older.

Informal caregivers do not receive pay for the care they provide. This differentiates them from **formal caregivers** (such as personal care attendants, home health aides or public health nurses) who usually work for an agency and receive pay to provide care.

Informal caregivers provide assistance to someone who is experiencing limitations in **activities of daily living** (ADLs) such as eating, bathing, dressing, toileting or ambulating and/or **instrumental activities of daily living** (IADLs) such as shopping, preparing meals, medication management, managing money, transportation or doing basic housework chores. Without assistance in these areas, care recipients would eventually have to move from their homes to a residential care setting where these services would be available.

Because of the chronic nature these limitations in ADLs and IADLs cause, informal caregiving situations tend to be long-term situations. For many, changes in the health care system and in medical technology are pushing caregiving well beyond its bounds of just 10-15 years ago. New medicines and treatments that allow people to leave the traditional hospital setting and return home sooner, especially the elderly, have also thrust family caregivers into new roles. Now many caregivers must oversee the in-home use of sophisticated machines such as feeding tubes and respirators that before were the bailiwick of only highly trained health care professionals. Often caregivers must also administer multiple medications properly, often for several medical problems, or risk complications and the re-hospitalization of the care recipient.¹ Thus, to some extent, the caregiving experience mirrors the trend seen in other areas of long-term care: more

intense care that use to be provided in hospitals is now provided in other residential care settings and by other long-term care services.

Other important distinctions regarding caregiving that will be used in this report include:

- Primary caregivers who have the lead role in providing direct care to care recipients versus secondary caregivers who assist primary caregivers;
- Full time caregivers versus part time caregivers (who may be long distance caregivers);
- Caregivers who live with the person being cared for versus those that live separately; and
- Personal relationship to caregiver recipients: a spouse will approach the caregiving situation with a different set of expectations, history and needs from a child, relative or friend.

OVERVIEW OF INFORMAL CAREGIVING

Long-term care differs from other types of health care in that the goal of long-term care is not to cure an illness, but to allow an individual to attain and maintain an optimal level of functioning. Long-term care encompasses a wide array of medical, social, personal, and supportive and specialized housing services needed by individuals who have lost some capacity for self-care because of a chronic illness or disabling condition.²

When most people think of long-term care, they usually think of older people in nursing homes and hospitals, or government programs like Medicaid and Medicare. However, families, not facilities and government programs are the bedrock of long-term care. Informal caregiving by families and friends continues to be the way most people receive the long-term care services they need. It's family and friends assisting someone with a physical limitation or medical condition so they can remain at home. And it's not just older people that receive long-term care - people of all ages benefit from informal caregiving.

The most commonly quoted figure for the number of informal caregiving situations in the nation is 22.4 million households. This equates to about one in every four households in America that is involved in informal caregiving. The degree of caregiver involvement has remained fairly constant for more than a decade, bearing witness to the remarkable resilience of the American family in taking care of its older persons. This is despite increased geographic separation, greater numbers of women in the workforce, and other changes in family life. Thus, family caregiving has been a blessing in many respects. It has been a budget-saver to governments faced annually with the challenge of covering the health and long-term care expenses of persons who are ill and have chronic disabilities.³

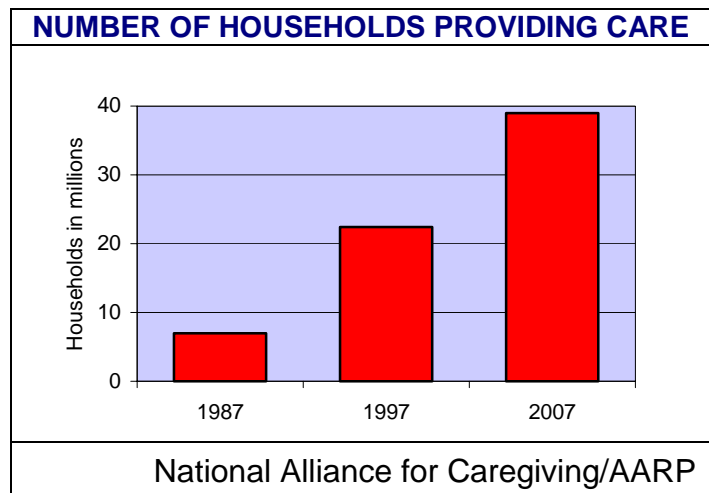
There are many factors that contribute to the prevalence of informal caregiving. A combination of rugged individualism, a strong belief that families should take care of their own and an aversion to using formal services either because they are perceived as welfare programs or are seen as too costly all contribute to an atmosphere conducive to informal caregiving in Montana. For most care recipients, cost savings of informal caregiving are secondary to their ability to remain independent in their own homes.

Montana's rural nature heightens the need and importance of informal caregiving. In most rural communities, low population density, lack of medical services, infrastructure and trained staff as well as limited state and/or federal funding makes it difficult to develop and maintain many of the health care services that allow people to remain in their homes. Without the help of informal caregivers, most people needing care would be forced to move to someplace that had services or move into an institutional setting.

Care needs usually start with instrumental activities of daily living, such as help with transportation to medical appointments or shopping, or assistance with balancing a checkbook. As limitations increase, care needs progress to more personal types of care, such as eating, dressing and bathing. Friends and neighbors are more likely to provide assistance with instrumental activities of daily living than with the more personal activities of daily living. In informal caregiving situations, formal caregiving is usually a supplemental service used when a caregiver is unable to provide assistance or as caregivers burn out. When the need for care becomes too great, caregivers seek a residential placement to meet care needs of the care recipient.

SOME CAREGIVING STATISTICS

- The largest number of people who need long-term care are elders. Approximately 53% of people needing long-term care are people age 65 or older while 44% are working age adults between 18 and 64, and 3% are children under age 18.⁴
- More than 22.4 million households are informal caregivers, providing care within a 12 month period to a family member or relative 50 years of age or older who has at least one limitation in their activities of daily living. The number of households providing care between 1987 and 1997 tripled.⁵
- About 7.3 million informal caregivers provide help to people 65 years of age or older who are disabled and living in the community.⁶
- Informal caregivers provide 120 million hours of informal care per year.⁷
- If the services provided by informal caregivers had to be replaced with paid services, it would cost an estimated \$196 billion.⁸
- Estimates indicate that 25% of the entire American workforce provided informal care during 1996.⁹
- The estimated cost of informal caregiving in terms of lost productivity to U.S. businesses is between \$11.4 billion and \$29 billion annually.¹⁰



- Nearly a third of caregivers are themselves over the age of 60. One quarter are between 65 and 75 years old, and another 10 percent are at least 75 years of age.¹¹
- Approximately 75% of those providing care to older family members and friends are female.¹²
- As the number of senior citizens increases, the prevalence of informal caregiving will grow. In 2000, more than 7 million older adults have long-term care needs. More than 10 million will have such needs by 2020 and 14 million by 2040.¹³
- 65% of older persons with long-term care needs rely exclusively on family and friends to provide assistance. Another 30% will supplement family care with assistance from paid providers. Only 5% rely exclusively on paid help.¹⁴
- 6% of all adults age 65 or older need help from another person with activities of daily living (such as eating, bathing, dressing, or walking). Adults 85 years of age or older are more than 6 times as likely to need assistance with activities of daily living as people who are 65-74 years of age. For this age group, women were more likely than men to need assistance.¹⁵

THE NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM

A growing body of evidence confirms that the provision of supportive services can diminish caregiver burden, permit caregivers to remain in the workforce, and enable people with caregiving needs to remain in community settings, possibly delaying or avoiding placements in institutional settings (like nursing homes and assisted living facilities). Congress responded to the growing need to provide supportive services to informal caregivers by developing the National Family Caregiver Support Program (NFCSP) as part of the 2000 Reauthorization of the Older Americans Act. The goal of the NFCSP is to help caregivers early on in their caregiving careers to prevent burnout.

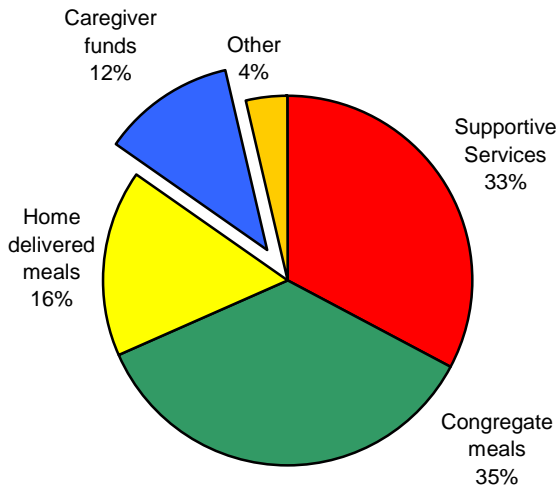
The NFCSP targets two separate groups of caregivers:

- **Family caregivers:** Any adult family member or other individual who is an informal provider of in-home and community care to a person 60 years of age or older. This includes caregivers who are non-relatives, such as friends and neighbors.
- **Grandparents and relative caregivers** of children 18 years of age and younger. The caregivers must be a grandparent or step-grandparent of a child or a relative of a child by blood or marriage, be over age 60, live with the child, act as the primary caregiver of the child, and have either a legal relationship to the child or raise the child informally. Also included in this group are parents who are 60 years of age or older and are the primary caregivers of a child who has mental retardation or a developmental disability. Half a million people who have mental retardation or another developmental disability (or 12.5% of the total population with mental retardation or a developmental disability) are children or adults that live with parents over age 60.¹⁶

Montana is completing its third year of funding for the National Family Caregiver Support Program. NFCSP funding has allowed the Aging Network to augment existing services as well as provided the opportunity to expand services into previously underserved areas of need.

Funding for the NFCSP has increased every year since its inception in 2001. Funding levels were \$125 million in fiscal year 2001 and increased to \$155.2 million by fiscal year 2003. Most funds are allocated to states through a congressionally mandated formula that is based on a proportionate share of the age 70 and older population.

FEDERAL FUNDING FOR MT AGING SERVICES



After in-direct costs, the State passes all NFSCP funds through to the Area Agencies on Aging (AAAs). NFCSP funds have to be spent in one of five broad categories: Information and education; Assistance; Caregiver Counseling (including caregiver and grandparent support groups); Respite; or Supplemental Services. Each Area Agencies on Aging has the flexibility to determine how they will use caregiver funds within the counties they serve. Some AAAs set broad area guidelines for the use of these funds based on input from their advisory board and local county councils. Other AAAs allowed individual counties to decide how best to use funds at the local level. Area Agencies receive funding for the NFCSP based on the state funding formula.

The following are some major challenges Montana faces in developing local NFSCPs.

- Developing comprehensive programs with limited budgets is very difficult. When NFCSP funds are allocated across 10 area agencies, budgets at the Area level range from about \$17,000 in Area 10 to \$100,000 in Area II. On a per county basis, the range of NFCSP funds goes from about \$800 in Petroleum County to about \$44,600 in Yellowstone County. Both coincidentally are in Area II. The median amount of NFCSP county funding is \$4250.
- In many areas, it is not financially possible to offer all of the five services, especially if services did not exist prior to the NFCSP. Local aging services providers must balance consumer needs against fiscal and programmatic realities. Low population density and geographic distances are constant barriers that many providers struggle with in developing and implementing new services.
- Reaching caregivers at a point when they are most likely to accept help and before they are in crisis.

- Developing ways of helping caregivers to self-identify with their role as caregivers and helping them recognize their need for help in their caregiver role.
- Reaching employed caregivers and employers of working caregivers, especially in rural Montana where most employers are small businesses.
- Reaching out to and serving grandparents. Since they are caring for children, most grandparents tend to look to children services rather than aging services for assistance and support in their caregiving role.
- Coordinating new NFCSP services with existing state programs while avoiding duplication of services and conflicts in program administration. Respite is a prime example of a service where coordination is necessary.
- Recruiting and retaining qualified staff to work in all NFCSP services.
- Developing viable payment strategies for services that make the services more sustainable, yet still affordable to caregivers. Most of the current aging services are provided on a voluntary contribution basis. Many agencies are unfamiliar or uncomfortable with implementing alternative payment methods, such as slide fee scales. Additionally, aging programs tend to be a provider of last resort - they provide services to those not covered by government programs like Medicaid or private insurances.
- Collecting program data on caregivers, care recipients and services provided.

FUTURE TRENDS IN CAREGIVING

The future of informal caregiving will be affected by a number of demographic, cultural and health trends. The need for informal caregiving is certain to only grow. We cannot take for granted however, that current patterns of informal caregiving can be sustained. Of a number of factors that will make it difficult to sustain the same level of informal caregiving, the primary ones are:

- continuing high numbers of women employed full time;
- continued growth in the number of people requiring long-term care, mainly as a result of population aging;
- out-migration of adult children to urban centers for employment; and
- an increase in the proportion of persons age 85 and older, the group most likely to need long-term care.

The increasing participation of women in the paid work force, the postponement of marriage, the greater prevalence of divorce, and the increase in childbearing outside of marriage all have affected families. Increasing life expectancy has brought two major changes in family structure and function. First, more generations are alive at any one time, which increases the size and breadth of families. Second, the longer average life expectancy has increased the length of time families are likely to include a family member with an age-related disability. It is too soon to know how these changes will affect American family life. Much will depend on trends in disability among older Americans: the

proportion of later life spent with a disability, the number of years an older person may need assistance with daily activities, and the age at which that assistance is needed. As the population ages, primary caregivers (whether spouses or adult children) will be much older themselves on average, making them less able to provide the level of informal care they might have given when younger.¹⁷

The baby boomers may be at the forefront of yet another phenomenon. Despite their numbers, baby boomers have had relatively few children, sparking concern that those who may need care or assistance in advanced age will have a small circle of immediate family to draw on.¹⁸

However, new research finds that the concept of family for the elderly of the 21st century will be very different from the makeup of families of the elderly today. Unprecedented rates of divorce and remarriage are already redefining families of baby boomers. When the boomers become the elderly of the future, they will have impressive numbers of stepchildren and step grandchildren, expanding the numbers of family members on whom the disabled may rely, if needed. For the younger generation, these changes in family structure could increase the potential for caregiving responsibilities but also offer more opportunity to share any burdens among siblings. There may be a need to reconsider traditional views of support ratios for retirement and long-term care and to look more closely at the dynamics of intergenerational relationships generally.¹⁹

The full 2003 State of Aging report is available at <http://www.dphhs.state.mt.us/sltc/>. Look under the **What's New** tab on the left of the screen.

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- 1 National Alliance for Caregiving Toward a National Caregiving Agenda: Empowering Family Caregivers in America 7/2001
 - 2 U.S. Senate Special Committee on Aging hearing: February 2000
 - 3 DHHS/Administration on Aging What We do Makes a Difference: Family Caregiver Fact Sheet 8/2003
 - 4 Family Caregiver Alliance: Selected Long-Term Care Statistics 2002
 - 5 National Alliance for Caregiving/AARP Family Caregiving in the U.S.: Findings from a National Study Washington, D.C. 1997
 - 6 American Society on Aging information at <http://www.careguide.com/>
 - 7 DHHS/Administration on Aging NFCSP: Selected Issue Briefs Smith, Gary, Doty, Pamela and O'Keeffe, Janet Supporting Informal Caregiving (under Medicaid) 2000
 - 8 Family Caregiver Alliance: Selected Long-Term Care Statistics 2002
 - 9 Family Caregiver Alliance: Women and Caregiving – Facts and Figures 2003
 - 10 MetLife Mature Market Institute The MetLife Juggling Act Study: Balancing Caregiving with Work and the Costs Involved Metropolitan Life Insurance Company 11/1999
 - 11 American Society on Aging information at <http://www.careguide.com/>
 - 12 Dept. of Health and Human Services Informal Caregiving: Compassion in Action. Washington D.C. 6/1998
 - 13 Wagner, Donna, "The Development and Future of Workplace Eldercare," Dimensions of Family Caregiving: A Look Into the Future, Monograph, prepared for a national conference September 12, 2000, sponsored by MetLife Mature Market Institute
 - 14 Family Caregiver Alliance: Women and Caregiving – Facts and Figures 2003)
 - 15 DHHS/CDC 2002 National Health Survey 3/2003
 - 16 DHHS/Administration on Aging NFCSP: Selected Issue Briefs Smith, Gary, Doty, Pamela and O'Keeffe, Janet Supporting Informal Caregiving (under Medicaid) 2000
 - 17 DHHS/Administration on Aging NFCSP: Selected Issue Briefs Smith, Gary, Doty, Pamela and O'Keeffe, Janet Supporting Informal Caregiving (under Medicaid) 2000
 - 18 National Institute of Health New Release Stepchildren May Expand Pool of Caregivers for Baby Boomers 12/1997
 - 19 National Institute of Health New Release Stepchildren May Expand Pool of Caregivers for Baby Boomers 12/1997